

SOCIAL FACTORS RELATED TO QUALITY OF LIFE AMONG HIV INFECTED CHILDREN IN UBON RATCHATHANI PROVINCE, THAILAND

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Abstract. A cross-sectional study was conducted to determine the social factors and quality of life of HIV infected children attending the Pediatric Infectious Disease Clinic, Sappasithprasong Hospital, Ubon Ratchathani Province, Thailand. Data were collected during October-November 2008, by interviewing caretakers and their children using a structured questionnaire. The children's families were in need of improved social support (84.5%), since community resources provided limited support, such as clothes, food, financial support, consultation, and information. The HIV infected children's quality of life needed improvement (78.7%). The factors associated with quality of life included having others as main caretakers (OR 4.64, 95%CI 1.45-14.78), parental death (OR 4.19, 95%CI 1.55-11.31), age of caregivers above 45 years old (OR 9.52, 95%CI 2.62-34.53), and family income less than THB 5,000 per month (OR 5.25, 95%CI 1.14-23.39). However, on multivariate analysis, only age of caregiver was a significant predictor for quality of life of the child. Children who were cared for by caregivers aged 45 years or above had a better quality of life than those whose caregivers were 20-45 years old (OR 6.32, 95%CI 1.12-35.62). Therefore, to improve quality of life among HIV infected children, age of caregiver is an important factor to be considered. Government and non-government organizations should focus on supporting caregivers in terms of food, financial, and emotional support based on resources available in the community.

Key words: quality of life, social factors, HIV, children, Thailand

INTRODUCTION

In 2006, the number of children world-

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wide living with HIV less than 15 years old was 2.3 million; 530,000 children under age 15 years became newly infected with HIV and there were 380,000 AIDS related children deaths (UNAIDS, 2006). In 2005, the Thai Working Group on HIV/AIDS Projection estimated the number of children younger than 14 years old with HIV infection was about 50,620. They predicted by 2006 there would be 53,400 HIV infected children younger than 14 years

old in Thailand (Bureau of Epidemiology, 2004).

At present, highly active antiretroviral therapy (HARRT) for HIV infected individuals improves length and quality of life (QoL). This study was carried out among caregivers to measure QoL of HIV infected children and to evaluate for significant differences in QoL between children with normal CD4 levels and those with decreased CD4 levels (Oberdofer *et al*, 2008). A study in the United States on the impact of HIV infection and antiretroviral treatment on QoL among children 5 to 11 years old reported worse health perceptions, physical resilience, physical functioning, and social/role functioning for QoL (Lee *et al*, 2007). A study in Thailand reported that 92.2% of HIV infected children had a good quality of life where social support, care giving, treatment, and adequate financial support were provided (Aeamlaor, 2001). This shows not only medical factors (eg, treatment, medical services) but social factors influence QoL of HIV infected children.

Knowing school age children's perceptions regarding their Health Related Quality Of Life (HRQOL) before they enter their preteen years may be important for parents, school nurses and teachers, in order to distinguish children who are in need of extra support and encouragement from professionals (Svavarsdottir and Orlygsdottir, 2006).

The QoL of HIV infected children in Thailand has received little attention in health research. The objective of this study was to determine the social factors, namely social support, socio-demographic characteristics of children, and socio-demographic characteristics of caretakers associated with quality of life among HIV infected children.

MATERIALS AND METHODS

Study population

This was a cross-sectional study of 114 HIV infected children who contracted HIV via mother to child transmission. The children were 8-15 years old who had received medical care from the Pediatric Infectious Disease Clinic at Sappasithprasong Hospital. There have been no previous studies done at the Pediatric Infectious Disease Clinic, Sappasithprasong Hospital, in northeastern Thailand. The results may be used to compare with studies from other areas. The inclusion criteria were children registered at the hospital before February 2007. Their respective caregivers were also recruited into the study. Exclusion criteria included children unable to communicate due to severe symptoms related to AIDS or opportunistic infection, and caregivers caring for HIV infected children for less than 6 months. Purposive sampling was used to select participants. The sample size of the study was calculated using the following formula (Yamane, 1973): ($N = 114$, $e = 0.05$, at $\alpha = 0.05$)

$$n = \frac{N}{1 + N(e)^2}$$

The calculated sample size was 89. The total number of eligible study children was 114; three HIV infected children did not want to participate in the study, and one was unable to communicate because of severe symptoms related to AIDS, thus there were a total of 110 participants in this study.

Data collection

A detailed explanation of the study was given to the caregivers and children before informed consent was obtained. The participants were interviewed by trained interviewers. The data were collected

using a questionnaire to determine social factors, social support and quality of life.

The social support was categorized into 5 types of support: food, clothes, finances, consultation, and information. The 5 sources of support were: family, neighbors, community, the government, and non-government organizations. The types of support were divided into "emotional" and "practical" (or instrumental). Emotional support included "information" support, where support sources provided information to help the subjects in problem solving. Another important component of emotional support was self-appraisal. Practical support was manifested in many forms, including practical help and financial support (Biscoti and Bergerman, 1999).

QoL was assessed based on the concept of Zhan (1992) which consisted of 5 dimensions: physical functioning, school functioning, emotional functioning, social functioning, and life satisfaction. Each dimension was developed from a literature review in a previous study (Kanda, 2004): physical functioning and school functioning used items from the Pediatric Quality of Life Inventory (version 4.0 Generic Core Scales in Healthy and Patient Populations) (PedsQL™) (Vani *et al*, 2001). This study modified Vani's criteria and scoring was done as in a previous study (Kanda, 2004). Emotional functioning and social functioning was adapted from a School Children Behavioral Check list for parents (Manual for Caring for Mental Health for Teachers) (Department of Mental Health, 2003). Life satisfaction was adapted from the Multi-dimensional Students' Life Satisfaction Scale (Manual for the Multidimensional Students' Life Satisfaction Scale) (Huebner, 2001). Questions had three possible responses: Never, Sometimes and Always.

Emotional functioning, social functioning and life satisfaction were responded to by the children. The questions did not directly refer to HIV but focused on social interactions and emotional well-being. Physical and school functioning were answered by the caregivers. The subjects were divided into two groups: good QoL or need for improvement in QoL. For this study, we used Vani's items for the questionnaire, but the criteria, method and scoring were those by Kanda (2004). The scores were categorized as follows: scores $\geq +1$ SD = good; scores $< +1$ SD = need for improvement. The instruments were pilot tested by 20 caregivers and children who had similar characteristics to those in the study. The Cronbach alpha coefficient was used to calculate the reliability of the social support questionnaire and the QoL questionnaire. The reliabilities of the questionnaires were 0.91 and 0.78, respectively. CD4 counts and classification of their illness were collected from the medical records of the children.

Statistical analysis

SPSS version 17.0 was used for data analysis with the statistical level of significance set at 0.05. Descriptive statistics, such as frequencies, percentages, means and standard deviations, were used for analysis. Bivariate analysis was used to determine factors associated with quality of life in HIV infected children by calculating a crude odds ratio and its 95% confidence interval. Multiple logistic regression was used to determine predictors for quality of life in children after controlling for multiple covariates simultaneously.

Ethical clearance

This study was approved by the Ethics Committee of the Faculty of Tropical Medicine, Mahidol University (EC Submission No.: TMEC 08-027, 26 August

Table 1
Socio-demographic characteristics of the study children.

Variable	Number <i>n</i> =110	Percent
Gender		
Male	49	44.5
Female	61	55.5
Age (in years) (Range=8-15, Mean=11.75, SD=1.94)		
8-12	70	63.6
13-15	40	36.4
Family structure		
Nuclear	40	36.4
Extended	70	63.6
Main caretakers		
Mother/Father	46	41.8
Grandmother/Grandfather	48	43.7
Relatives	13	11.8
Foster parent	1	0.9
Other	2	1.8
Both parents alive		
Yes	62	56.4
No	48	43.6
CD4% (Range=2-38, Mean=23.36, SD=8.56)		
CD4 count (cell/ μ l) (Range=30-1,802, Mean=675.75, SD=35.35)		
<200	10	9.3
200-499	26	24.0
\geq 500	72	66.7
CDC classification		
N	6	5.6
A	36	33.3
B	48	44.4
C	18	16.7

Table 2
Socio-demographic characteristics of the caregivers.

Variable	Number	Percent
	<i>n</i> =110	
Gender		
Male	25	22.7
Female	85	77.3
Age (in years) (Range=23-80, Mean=48.95, SD=13.81)		
20-45	57	51.9
>45	53	48.1
Education level		
Primary school	74	67.3
Secondary school	22	20
Diploma/vocational	4	3.6
Did not attend school	10	9.1
Occupation		
Civil services/state enterprise	1	0.9
Agriculturalist	52	47.3
General employee	18	16.4
Merchants	19	17.2
Other	2	1.8
No work	18	16.4
Family income/month (Baht) (Range=400-20,000, Mean=3,130, SD=2,748.56)		
\leq 1,999	38	34.9
2,000-4,999	41	37.6
5,000-9,999	29	26.6
\geq 10,000	1	0.9

USD 1 \approx THB 32

2008) and the Ethics Committee of Sappasithprasong Hospital, Ubon Ratchathani (EC Submission No.: 023/2551, 14 October 2008).

RESULTS

About half (55.5%) of the children were female, mean age was 11.65 (SD \pm 1.94), and

most subjects had a CDC HIV classification of category A or B (33.3% and 44.4%). Seventy percent of children had a CD4 count \geq 500 cells/ μ l. and 9% had a CD4 count < 200 cells/ μ l. The CD4% ranged between 2-38, with a mean of 23.36, (SD \pm 8.56). The majority of the children lived in extended families (63.6%). The main caregivers for the children were mothers/fathers (41.8%); only three children were cared for by foster parents or others. About 56.4% of children had parents who were both alive (Table 1).

Table 3
Social factors and quality of life of children ($n = 108$).

Variable	QoL (%)		Crude odds ratio(95% CI)	Adjusted odds ratio(95% CI)	p-value
	Good	Need for improvement			
Gender of children					
Male	14.3	85.7	1.00	1.00	
Female	27.1	72.9	2.23	1.63	
			(0.83-5.97)	(0.52-5.07)	0.397
Age of children (years)					
8-12	15.9	84.1	1.00	1.00	
13-15	30.8	69.2	2.34	1.76	
			(0.92-5.98)	(0.55-5.60)	0.338
Main caretakers					
Parents	8.7	91.3	1.00	1.00	
Others	30.6	69.4	4.64	0.51	
			(1.45-14.78)	(0.06-3.82)	0.512
Both parents alive					
Yes	11.3	88.7	1.00	1.00	
No	34.8	65.2	4.19	3.21	
			(1.55-11.31)	(0.78-13.20)	0.105
Age of caregivers (in years)					
20-45	5.7	94.3	1.00	1.00	
>45	36.4	63.6	9.52	6.32	
			(2.62-34.53)	(1.12-35.65)	0.036
Education of caregivers					
Did not attend school	50.0	50.0	1.00	1.00	
Primary school	20.3	79.7	0.25	0.37	
			(0.05-1.13)	(0.06-2.02)	0.253
Secondary school	15.4	84.6	0.18	0.46	0.490
Diploma/vocational			(0.03-1.04)	(0.05-4.05)	
Family income/month (Baht)					
>5,000	6.7	93.3	1.00	1.00	
≤5,000	27.3	72.7	5.25	3.01	
			(1.14-23.99)	(0.56-16.28)	0.199

QoL: quality of life; USD 1 ≈ THB 32

About 77.3% of caregivers were female with a mean age of 49.0 years ($SD \pm 13.8$). Sixty-seven point three percent of caregivers had completed primary school. Nearly 50% of caregivers were farmers, followed by merchants and general employees (17.3% and 16.4%); 16.4% were unemployed. The average monthly

family income was THB 3,130; 37.6% had a monthly family income of THB 2,000-4,999 (Table 2). Seventy-eight point seven percent of children needed improvement in quality of life, while 21.3% had a good level quality of life (mean \pm SD, 50.87 \pm 8.24).

On bivariate analysis, the factors significantly associated with QoL were the

Table 4
Knowledge about HIV/AIDS in caregivers and social support for HIV infected children and their families.

Variable	Number <i>n</i> = 110	Percent
Social support (Range = 0-25, Mean = 11.70, SD = 4.68)		
Good	17	15.5
Needs improvement	93	84.5
Knowledge (Range = 4-23, Mean = 16.25, SD = 4.36)		
Good	32	29.1
Needs improvement	78	70.9

Table 5
Percentage of social support for HIV infected children's families (*n*=110) (%).

Type of support	Family	Neighbor	Community	Government	NGOs
Food	95.5	56.4	8.2	31.8	12.7
Clothes	95.5	48.2	10.9	30.9	14.5
Financial	92.7	33.1	8.2	57.3	15.5
Consultation	92.7	60.0	15.5	67.2	51.8
Information	90.9	51.0	19.1	66.3	52.7

NGO, non-government organization

main caregivers, if the parents were alive or not, the age of the caregivers being above 45 years and a family income THB $\leq 5,000$. Multiple logistic regression revealed the only significant association with quality of life in HIV infected children was the age of the caregivers being >45 years old (OR 6.32, 95%CI 1.12-35.62) (Table 3). Eighty-four point five percent of families expressed need for improvement in social support for HIV infected children (Mean \pm SD, 11.70 \pm 4.68) (Table 4). More than 90% of families with HIV infected children received social support from their families, followed by neighbors which supported with food, clothes, and consultations (56.4, 48.2, and 60.0%, respectively), and government assistance, which provided finances, consultations, and infor-

mation (57.3, 67.2 and 66.3%, respectively). The communities provided small amounts of all types of social support for these families. Families received nearly 50% of their consultation and information support from non-government organizations (NGOs) (Table 5).

DISCUSSION

Our study examined QoL in HIV infected children and explored social factors related to QoL. We found a large number of HIV infected children (78.7%) needed improvement in QoL. This study is in a contrast to a study by Aeamlaoir (2001) who found 92.2% had a good QoL since they were cared for by social welfare organizations. About 82% of HIV infected

children in this study lived in rural areas; their QoL could be different from children who were cared for by social welfare organizations and received appropriate care, treatment, and adequate financial support. This study also showed that girls had a better QoL (27.1%) than boys (14.3%).

In our study, 63% of HIV infected children lived in extended families, similar to studies from Uganda and China, which found that those who were infected with HIV typically lived in extended family networks (Rotheram-Borus *et al*, 2005). The extended family provides HIV infected children the emotional nurturing and socialization that is the primary role of the family. This allows HIV infected children to be well-adjusted. In Thai society, care of children by grandparents is common (Sunpuwan, 2001).

Surprisingly, children with monthly family THB \leq 5,000 had 5.25 times better QoL than those with family incomes of THB $>$ 5,000 per month. One reason may be that children from families with higher incomes tended to request a need for more improvement in social and family support. Eighty-seven point five percent of children cared for by caregivers with family incomes THB $>$ 5,000 per month were merchant of government/private employee families.

There was a significantly higher QoL in HIV infected children who had no immune suppression than in children with immune suppression in one study (Oberdorfer *et al*, 2008). The results of that study are consistent with our study results. The asymptomatic children had a higher QoL (62.2%) than the symptomatic children (18.8%) in our study.

In our study, parents or caregivers who were still alive was significantly associated with QoL. Interestingly, children

whose parents had died had a 4.19 times better QoL than those whose parents were alive. Those children who were cared for by others (grandparents, relatives, foster parents) had a 4.64 times better QoL than those who were cared for by parents. On multivariate analysis, however, these factors were not significant. The only significant factors associated with QoL on bivariate and multivariate analysis was age of caregivers. The children whose caregivers were age \geq 45 years old had a better quality of life than those whose caregivers were 20-45 years old (OR 6.32, 95%CI 1.12-35.62). One reason for these findings may be that parents were unable to care for their children because they had a health problem related to HIV infection, were unemployed, or went to work in another province which is typical for younger generations in northeastern Thailand. Thus, they could not give good care for their children. The result of another study also supports this finding; caregivers who were HIV positive had poorer physical and emotional health than non-infected caregivers (Amodei *et al*, 1997). HIV positive caregivers are at greater risk of experiencing a greater economic burden, social impact, and personal strain than HIV negative caregivers (Lesar and Maldonado, 1997). There was no significant association between social support for the HIV child's family and QoL. This finding is in contrast with a previous study, which found social support was a factor positively affecting basic caring in families with AIDS orphans (Wiboonchai, 2001). This may be related to the fact the families of HIV infected children limited themselves to their community. They expected only a small amount of support, such as food, clothes, financial support, consultations, and information from community sources (Table 5). In a similar study

from northern Thailand, the community provided little help to orphans and their families within several areas: physical, psychological, social and educational support. Although the families received some help from government and non-government organizations, the help remained inadequate (Sunpuwan, 2001). Another study from southwestern China many HIV infected children whose parents were infected with HIV or had died from HIV were living in stressful environments with minimal support from the community (Yang *et al*, 2006).

In conclusion, factors affecting QoL in HIV infected children were the main caregiver, biological parents death, age of caregiver > 45 years old, and monthly family income < THB 5,000. The HIV-infected children's quality of life needed improvement and the caregivers needed improved knowledge (Table 4). The families of HIV-infected children were in need of improved social support. Non-government and government organizations may consider the age of caretakers in self help groups and those who should receive training about providing care for and supporting HIV infected children. Providing knowledge about HIV/AIDS needs to focus on caregivers and be continuous, educating regarding symptoms, prevention, treatment, and caring for people living with HIV/AIDS. Referral systems need to be set up to provide support for people living with HIV/AIDS. HIV infected children came for follow-up each month allowing the Comprehensive Patient Treatment Team to closely monitor them allowing recognition and management of problems occurring among HIV infected children so the quality of life of those children may be improved. A limitation of our study was that it was cross-sectional and hospital-based conducted at only one hospital.

Therefore, external validity was limited. We found important factors than can be modified and applied to other settings to provide better care for children living with HIV/AIDS.

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